

THE MINNESOTA NETWORK OF NOT-FOR-PROFIT PROVIDERS OF MENTAL RETARDATION SERVICES

A Statement Opposed to bill  
S-2053, which is pending in  
the Senate of the United States.

Respectfully Submitted -- August 9, 1984

The Minnesota Network of Not-For-Profit Providers of Mental Retardation Services (hereafter referred to simply as "the Network") is composed of representatives from eight organizations including: Hammer Residences, Clara Doern Residence, Lutheran Social Services, Hiawatha Homes, Dakota's Children, Inc., Muriel Humphrey Residences, Homeward Bound and Rolling Acres. The organization is a forum to exchange ideas and unify concerns regarding the success of existing care methods, and to explore possibilities that might lead to more comprehensive and cost-effective care in the future. This group represents the care standards afforded to 687 residents. It is because we, as medium-sized facilities which serve between 36 and 103 persons, believe services at our locations (and those like ours nationwide) will be adversely affected by bill S.2053 that we stand united against passage of the bill in its current form.

IDENTIFICATION

## Introduction

Minnesota has always been recognized as a leader in developing care for the mentally retarded. As the de-institutionalization revolution swept America in the early 1970s, this state was in the forefront in unfolding comprehensive, sensitive answers to difficult questions. By the 1980s, Minnesota had clearly established itself as a trailblazer in services for the mentally handicapped, having shifted significantly more than 50 percent of its residents from large, institution-like facilities to smaller ones. In 1969, about 6200 residents lived in state institutions. At that time, only about 500 persons (this estimate is likely high) lived in neighborhood facilities. But in 1984, thanks to the success and prevalence of medium-sized facilities in the state, only 1800 remain institutionalized. A significant number of these mentally handicapped persons are now served by Minnesota's 41 medium-sized facilities (which have more than 15 residents, and unfortunately, would be adversely affected by bill S. 2053.

In effect, they provide the neighborhood influence and residential atmosphere available in a home, which bill S.2053 espouses, but unlike the proposed legislation, these facilities are also equipped to deal with those patients who need constant or specialized attention because of age, or reasons of physical, psychological or emotional health. Furthermore, these sites provide stability of staff personnel. A study by the University of Minnesota used a concept known as the close/move rate to give an indication of stability. This index gives a percentage yearly turnover for facilities handling mentally handicapped persons. Nationwide, the close/move rate was 42.1 in 1983, while

Minnesota -- dense in medium-sized facilities -- was strikingly below the average, at eight percent. The study found that "one method of increasing stability noted in the research was through ICF/MR certification." It is interesting to note that all of Minnesota's group residences are ICF/MR certified.

The point is that the state is already doing a tough job well. To make arbitrary alterations in the way the system will carry out its function, we think, would be a mistake.

In summary, it is clear that Minnesota, like each state, and like each mentally retarded individual, is unique in its characteristics, and thus in its needs. In order to meet these needs, it has devised a broad range of services to meet the broad and complex range of situations among mentally handicapped persons. That is, in striving to become conscious of the uniqueness of each mentally retarded person, Minnesota Network Administrators have accordingly developed a spectrum to meet these needs. To narrow the range of services, as S.2053 would do, would be to reduce the options available to residents of the state, and to inhibit our abilities to meet the needs of certain persons unique to their given age, physical abilities, physical health and level of mental retardation. The result would be an overall reduction of the quality of care and services for the mentally handicapped. Specifically, we wish to make four broad points, and then develop them: Bill S.2053, in its current form, would reduce and eventually eliminate on-going Medicaid assistance to residents at homes with more than 10 persons living there. (3 x Av. Minn. Household of 3.4), 2) Most sites that care for more than 15 persons are not

"institutions," 3) There is no conclusive evidence that "small is better," 4) thus in conclusion, it is the position of the Network that S.2053 offers an oversimplified answer to the very complex question of how best to care for the mentally handicapped.

Phasing out medium-sized facilities

Proponents and opponents of Bill S.2053 disagree on many things, but one point on which there is no variance is that funds will be withdrawn from mid-sized facilities over periods of ten or 15 years with no compensating factor. In effect, a major source of funding -- and thus a primary assurance of a certain level of services -- will be stripped away. And since there will be nothing to bridge the newly-opened gap, many of these facilities will close.

There are those who would argue that S.2053 would "not actually close down" these facilities, but merely withdraw Medicaid funds. But what other effect would it have if families who now have children with us are given two alternatives: move your kids, or lose Medicaid benefits. Surely most of these families will not be able to entirely bear the financial brunt of keeping their child where he is, and thus a de-stabilizing move will occur that will have immediate negative effects for the resident, and immediate devastating effects on the system. To one who would argue that Bill S.2053 does not deny freedom of choice, we would counter that yet, you are correct, but only within the context of complete financial security. But as we know, mental retardation knows no sexual, racial, ethnic, national, social or economic bounds.

Network members have noted with some alarm that the facilities being disassociated from Medicaid are at no time urged to maintain quality during the period of transition. The bill never mentions what is to become of those who exercise their right to choose, but become entangled in a mess of shifting governmental priorities as the quality

of care at these medium-sized facilities drifts away long before the last resident leaves.

Institution?

Perhaps this position statement should have begun with a discussion of the word "institution." Webster's New World Dictionary defines it as "an organization having a social, educational or religious purpose, as a school, church, hospital, reformatory, etc. By this definition, not only are small and medium-sized facilities "institutions," but every facility which services more than one resident is, too. Ridiculous? Well, how many people make an organization? A group? And who determines this? Our point is that the number 10 (three times the average Minnesota household of 3.4) is both arbitrary and restrictive. Further, assigning the term "institution" to community-based service facilities which likely will afford retarded persons the same amount of actual contact with neighbors as smaller group homes is an outright misnomer.

We believe there has developed somewhere along the way the mistaken impression that if groups of retarded persons get together, they are treated like lepers, and conversely, if there are only a few, they will be wholeheartedly embraced by the society at large. Both are false, but the second assumption is erroneous and dangerous. First, in attempting to rescue them from "institutions," some individuals will be thrust prematurely into situations too difficult for them to handle. There are any number of neighborhoods in big cities where people who have lived next door for years do not even speak to one another. How then, do we arrive at this naive, simplistic (though hopeful) answer to the problem, believing that "just letting them be normal" will make everything OK.

### The Need For Diversity

The need for diversity was likely best explained by the senators themselves. Bob Dole, chairman of the Senate Finance Committee: "I am anxious to examine all options, including a movement toward community-based services. But with respect to the disabled, as with any other single group, obviously no one solution is best for all. I am anxious to examine all options including a movement toward community-based care in the hope of coming to agreement on the best mix of services."

And Dave Durenberger, chairman of the finance committee's subcommittee on health: "Senator Chafee's intent to de-institutionalize where appropriate should be applauded, but closing all state institutions would be a grave mistake. We need to develop a continuum of care to meet the varied needs of this population group and to provide alternatives so that "choice" can be realized."

But this legislation would undermine diversity. S.2053 would phase ~~out~~ federal funding for "large" institutions over a 10-15-year period, depending on when the facilities were developed (15 years for facilities housing 16-65 residents, which opened within five years of the date the bill would be enacted, and 10 years for all other facilities with 16 or more residents.

Conclusions

Our conclusions are simple. The proposed legislation is too simplistic to be effective. It suggests that we throw out a tried and proven system of care for the mentally handicapped, and adopt another based on nothing more than theoretical ideas about size. There is no conclusive data which states it would be cost-effective either. In fact, Network administrators who have done comparative cost analysis studies have found it more expensive to care for an individual in a 6-bed, than a 24-bed facility, and in some cases, it is been shown to be totally impractical from a financial standpoint to put a resident requiring certain specialized care procedures into a small facility. The senators should consider all these factors. We have.